Commentary: Increasing Cultural Diversity in Pediatric Psychology Family Assessment Research

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Received January 9, 2011; revisions received March 2, 2011; accepted March 5, 2011

The clinical and validation studies published in this issue are very timely, as they continue to refine theoretical models and evidence-based family assessment measures for vulnerable pediatric chronic populations. The studies in this issue individually and collectively advance our understanding of what predicts and informs parental and family outcomes across a number of pediatric chronic illness groups. These findings will also be critical to advancing family-based clinical practice and treatments for children with chronic illnesses (Alderfer et al., 2008; Kazak et al., 2007). In total, the articles increase the potential to include nontraditional families, use multi-method and validated assessment tools, and to integrate family measures with other assessment tools so that we can take a comprehensive approach to assessment in our work as pediatric psychologists. While this special issue of JPP advances our understanding of family assessment and processes related to pediatric conditions, it also reveals the continued need to improve cultural sensitivity in pediatric and family assessment (Alderfer et al., 2008; Shudy et al., 2006). This editorial will discuss the challenges and opportunities for enhancing diversity in pediatric psychology family assessment research, as well as the implications for how culturally sensitive family assessment informs clinical practice and research for culturally diverse populations (Clay, Mordhorst, & Lehn, 2002; Ochieng, 2003; Wood, 2005).

Trends in publications confirm that the general pediatric family psychology and family assessment literature has increased over the past 25 years, most notably in the past 10 years when publication rates have more than doubled. Using JPP as the example to illustrate growth in trends over time, there will be more articles published on the topic of “family” in this issue than there were published on the topic of “family” in the year 1980 when there were total eight articles (and these numbers remained below 30 in most of the years in the 1980s). Much of the journal’s space focused nearly exclusively on child-focused articles with a behaviorally focused assessment and/or intervention. In contrast, when using “family” as a keyword in 2009, 118 articles were published in the journal, and in 2010, 77 such articles were published through the third quarter. When the key words were narrowed to “family assessment,” the number of published articles was 105 since 1980 and half of these 52 (50%) were published since 2003, highlighting the emerging trend to better integrate family assessment tools in pediatric research. Finally, when examining the number of articles with a “family assessment” and a “cultural” or “diversity” focus, the number of articles was fewer than five. This rate held true even when looking for articles written on specific racial or ethnic subgroups (e.g., using “family assessment” as a search term with “African American” or “Hispanic/Latino”). While JPP offers a great context for making the case for why attention should now be given to diversity issues in the field, trends are likely to be similar in other journals and in the broader literature.

With the publication of this issue, it is fitting to celebrate the evolution and progress of family assessment research in the field of pediatric psychology, while also acknowledging the gap that still remains in the family assessment literature with respect to cultural diversity. We have to find sensitive and valid methods and models for applying and translating family assessment concepts and
tools to diverse populations. In this way, we can ensure culturally sensitive assessment of key variables and develop culturally sensitive interventions to target critical outcome variables. In essence, there is considerable literature to support that health/illness and family are both influenced by cultural variables and that all of these variables are inextricably linked (Noël, 2010; Ochs & Shohet, 2006). For example, there may be aspects of culture that are relevant if family mealtime observational assessments are being applied to a general or diverse sample, as food/meal socialization (e.g., average length of the meal, where the family eats, who is at the meal) may differ considerably across racial or ethnic groups (Hammons & Fiese, 2010; Pierce, Crowell, & Ferris, 2006). The interpretation of other concepts (e.g., family communication/parental expressed emotion, family coping styles, family roles) may also have to be considered in light of cultural and contextual considerations.

In addition, it is important to ensure cultural sensitivity in family assessment given the number of racially and ethnically diverse children with pediatric chronic health conditions (Newacheck, Stoddard, & McManus, 1993). We must remember that the prevalence rates of sickle cell disease, asthma, obesity, and type 2 diabetes are far greater for African-American and/or Hispanic children than for nonminority children (Flores et al., 2002). For many other diseases, including epilepsy, congenital heart disease, muscular-skeletal diseases, cerebral palsy, anemia, bowel disease, juvenile arthritis, and spina bifida, the rates of minorities with the diseases is not insignificant (the rate of African or Hispanic-white children with the disorder is 50–200% of the prevalence of non-Hispanic white children with the disorder; Newacheck et al., 1993). While the case can be made for why diversity inclusion in family assessment research is important, perhaps the first step to enhancing diversity in family assessment research is to discuss some of the primary challenges and barriers to the conduct of and participation in family assessment research among culturally diverse groups. The second step will be discussing the possible solutions for overcoming these obstacles.

**Mistrust and Other Critical Barriers to Engaging Minority Populations in Pediatric and Family Assessment Research**

The participation of racial and ethnic minorities and other underrepresented groups in health, clinical and medical research is an essential element in providing effective health and mental health care delivery (Ford et al., 2007). The underrepresentation of ethnic minorities in research studies is of particular concern given the increased risk of health issues within this population (Armstrong, Crum, Rieger, Bennett, & Edwards, 1999; Ford et al., 2007; Moseley, Freed, Bullard, & Goold, 2007; Penner et al., 2009). In response, the National Institutes of Health (NIH) has, since 1993, mandated that all NIH sponsored research include ethnic minorities and women (Ford et al., 2007; NIH, 2002, 2003).

Many ethnic minority groups (e.g., Latinos/Hispanics, Asian/Pacific Islanders/Alaskan natives) are underrepresented in research studies (Ford et al., 2007; Naples-Springer et al., 2000). Researchers have identified particular challenges in the recruitment and retention of African-American participants (Armstrong et al., 1999; Huang & Coker, 2008; Moseley et al., 2007; Naples-Springer et al., 2000). Cultural mistrust of scientific research and the medical system due to experiences of discrimination has been the reason most often cited (Penner et al., 2009). Furthermore, research shows that many of the underrepresented populations are reticent to participate in government funded projects due to a long history of exploitation by health care providers and government institutions in this country and in others. These vulnerable populations may use history as a reference point for the potential dangers to participating in research.

The infamous Tuskegee Syphilis Study, in which 400 African-American men diagnosed with syphilis were studied but left untreated over their lifetimes, has been much discussed in the literature as contributing to African-American cultural mistrust of medical research (Jones, 1981). This is the classic example of racial bias and disrespect of African Americans involved in research studies (Ford et al., 2007; Kibler & Brisco, 2006), and it is often cited as one cause of the fear of becoming a victim of experimentation (Napoles-Springer et al., 2000).

In the past 20 years, even after guidelines were established to protect the rights of humans in research, ethical violations in pediatric research continue. In 1990, 1,500 6-month old African-American and Hispanic infants in Los Angeles were administered a non-FDA approved experimental measles vaccine to test the efficacy of the vaccine (Goliszek, 2003). In 1995, the New York State Psychiatric Institute allowed the administration of fenfluramine, a chemical which can cause anxiety, headache, lightheadedness, diarrhea, nausea, and irritability, to healthy 6- to 10 year-old African-American and Puerto Rican boys. In both cases, parents and children were not given full disclosure as to the nature of the research project or potential side effects (Horne, 2001). These examples highlight the importance of ensuring human protection for all, but
especially vulnerable populations including child, pediatric, and underrepresented populations.

There are a number of factors that contributed to a reluctance on the part of some ethnic minorities to participate in research studies, including a perceived lack of sensitivity on the part of researchers to minority concerns (Armstrong et al., 1999), doubts as to whether researchers give back to the community and treat minority participants respectfully (Napoles-Springer et al., 2000), lack of understanding of research studies and informed consent by African Americans (Freimuth et al., 2001), and stigma regarding health or mental health issues (Brelan-Noble, Bell, & Nicolas, 2006). Napoles-Springer et al. (2000) found that Latino and other non-English speaking communities expressed a preference for researchers who spoke their language and for written materials in their language. Researchers have also found that culturally diverse and minority participants prioritize pressing social needs, such as food and housing (Guerro et al., 2010; Napoles-Springer et al., 2000).

One of the growing number of pediatric research studies exploring cultural mistrust was a study conducted by Moseley et al. (2007) to understand African-American parents’ reluctance to enroll their children in pediatric research studies. Parents completed the Cultural Mistrust Inventory (CMI) which revealed that parents were very protective of their children and that their level of cultural mistrust was high. This is an important finding as there is a critical need for data on how to include more children and adolescents from underrepresented ethnic minority groups in pediatric research studies, given the diversity of the United States and given well-documented child health disparities among African-American and other minority populations. To address cultural barriers and mistrust, family assessment instruments must also be normed on at risk minority groups, as Celano, Klinnert, Holsey, and McQuaid demonstrated in this volume.

In their work with African-American children with autism, Hilton et al. (2010) identified potential barriers to minority participation in research studies. They found that restrictive eligibility criterion was one of the reasons for low participation rates of minorities. For genetic mapping reasons, many of the research projects required participation of the child with autism, both parents and a close in age sibling. Hilton et al. (2010) pointed out, that these criteria severely limited participation. Some of the disqualifying factors in their cohort included; single female led household, father of the child unreachable, diagnosis of autistic child occurred after 8 years old, and no full siblings. Hilton et al. (2010) spoke with 58 families who were willing to participate in autism research. Of those, only eight families met criteria. They pointed out that while in the past both parents and a sibling were important for statistical power and genetic mapping, new technology now allows for less stringent requirements in how families’ constellations can be constructed, allowing for the inclusion of more nontraditional families.

Similar findings were noted in a study examining barriers to research participation among persons of South Asian descent when examining two groups of parents: those who had and those who had not participated in research studies. One of the overall findings was that the recruitment strategies and criteria shaped who enrolled in studies. Although participants in both groups indicated that they wanted to know more about research, those who had not participated lacked awareness about potential studies or were ineligible for research studies due to educational, language, or other cultural barriers (Hussain-Gamble et al., 2004). A second finding was that studies may be inadvertently designed, due to time and budgetary constraints, such that participants with higher income, transportation, acculturation, and other factors are better able to learn about and participate in research. To ensure generalizability of research, being time and cost efficient in research should be balanced with the need to ensure inclusion (Yancey, Ortega & Kamanyika, 2006; Hussain-Gamble et al., 2004).

Opportunities to Ensure Diversity Inclusion in Pediatric Research Studies and Clinical Practice

The work covered in this month’s journal encompasses a variety of measures used across a broad spectrum of chronic illnesses in the pediatric population. Multi-modal methods are also used to assess aspects of the family in relation to the specific illness, i.e., family functioning, coping, impact of the illness, illness management, and family cohesion. This collective body of research advances the field of pediatric psychology and adds a necessary dimension to the strong tradition of behavioral assessment and intervention that has characterized the field. The review of this work provides clinicians and researchers with current data that reflect the level of adjustment, coping and functioning, etc. (to name a few) in the area of pediatric chronic illness.

The broader literature supports that multiple factors impact the decision-making process of individuals when considering clinical care and research (e.g., mistrust, awareness, previous experiences, etc.). Notably, the relationship between researcher to participant and clinician
to patient are extremely important in attaining the best possible results in both research and clinical practice (Bogart, 2001). Trust within the both groups has been found to improve relationships and increase follow-through with participation in research (Huang & Coker, 2008) and adherence to provider recommendations (Wissow, Brown, & Krupnick, 2010). A growing body of literature has documented effective strategies for addressing the issues of research participation and clinical engagement among ethnic minorities. Strategies emerging from the literature are useful in informing research and clinical practice.

It is important for researchers to adjust their recruitment and retention efforts according to the population (Huang & Coker, 2008). Researchers have also emphasized the importance of establishing ongoing, long-term community relationships that are based on mutual trust (Ford et al., 2007; Hilton et al., 2010; Huang & Coker, 2008; Napoles-Springer et al., 2000). This finding has underscored the need for the recruitment, training, and inclusion of ethnic minorities at all levels of the research process (Ford et al., 2007) and inclusion of community members, leaders, and key stakeholders in focus groups prior to the initiation of the research process (Napoles-Springer et al., 2000). Fisher, Burnett, Huang, Chin, and Cagney (2007), in their extensive review of interventions using culture to narrow racial disparities, noted the process of engaging individuals in addition to the research participant. For example, Jandorf, Gutierrez, Lopez, Christie, and Itzkowitz (2005) studied the use of “patient navigators” who are trained to help clients from the same culture negotiate complex health care systems. A number of researchers have also shown that it is beneficial to involve the family of potential participants in the decision-making process (Huang & Coker, 2008). This is particularly crucial for pediatric researchers working with children, adolescents, and their families. Kaslow et al. (2000) and Kaslow and Brown (1995) were among the first to demonstrate the importance of culturally sensitive interventions with family involvement for children and adolescents with sickle cell disease (SCD). Consistent with this approach, Schwartz, Radcliffe, and Barakat (2007) found that it was very helpful to have a support person from the patient’s extended family network involved in the intervention. All of these researchers have emphasized the importance of ongoing training in cultural competency for the members of the research team (Kaslow et al., 2000; Kaslow & Brown, 1995; Schwartz et al., 2007). In addition to the work of Kaslow and others, culturally sensitive research is newly emerging across a number of pediatric conditions and in Latino and other minority populations, providing a basis to advance family-centered and culturally sensitive clinical care (Davies, Contro, Larson, & Widger, 2010; Guerrero, Chen, Inkelas, Rodriguez, Ortega, 2010; Roach, Messmer, & Williams, 2010).

A number of other successful recruitment efforts with minority populations have been identified (Yancey et al., 2006). Hilton et al. (2010) emphasized the importance of working collaboratively with a trusted source of medical care in the community. Their findings corroborate the recommendations of other researchers to include ethnically targeted media advertising and address the many competing obligations and stressors that may interfere with participation, especially those of low-income minority families, such as child care, transportation, flexible evening or weekend hours or home-based or community outreach efforts, and providing monetary as well as non-monetary incentives (i.e., information and/or referrals to other community resources) (Armstrong et al., 1999; Ford et al., 2007; Hilton et al., 2010; Napoles-Springer et al., 2000).

Napoles-Springer et al. (2000, p. 685) found that African-American respondents in their study would be more likely to participate in research “if their concerns were openly addressed, if barriers to participation were reduced, and if tangible benefits of participation could be seen in their communities.” A number of researchers have also recommended that participants from diverse and underrepresented backgrounds be given an honest understanding of the risks involved in studies, as fears of negative health outcomes are more likely to be heightened in these populations (Ford et al., 2007; Glickman et al., 2008; Napoles-Springer et al., 2000).

Finally, Huang & Coker (2008) have also provided critical components to effective engagement and recruitment. They include: acknowledging participants’ perception of the work, ethnic, and racial diversity on clinical teams; building rapport with participants; educating the participants’ immediate community about the research; having informed consent; and offering incentives that consider the time, participation, and burden associated with research.

Psychologists providing clinical interventions to children, adolescents, and families, as well as those who are involved in clinical research, can benefit from the findings of research studies promoting strategies for increasing cultural sensitivity (Diamond et al., 2006; Schwartz, et al., 2007). Pediatric psychologists, particularly those involved in cross-cultural or cross-racial treatment, are likely to overcome cultural mistrust or healthy cultural suspicion when they take the time to establish therapeutic rapport and build trust before using intake and family assessment
forms (Boyd-Franklin, 2003). Research and clinical psychologists need to collaborate in the development of “joining modules” that would be included in the beginning of treatment manuals (before intake and family assessment instruments). While building in opportunities to strengthen rapport with families may present a challenge for those following standardized and evidence-based assessment and treatment protocols, such an approach may be effective in keeping families engaged in the research process.

Boyd-Franklin (2003) points out that efforts to establish a trusting relationship increase the likelihood of retention of minorities in research studies and in treatment. This process would be helpful with all clients but is essential with African Americans and other ethnic minorities who approach therapy and research with cultural mistrust. Establishing trust, sensitivity to cultural and ethnic differences, and building rapport/joining with participants are essential components to these relationships. (Coatsworth, Duncan, Pantin, & Szapocznik, 2006; Mitrani, Prado, Feaster, Robinson-Batista, & Szapocznik, 2003; Prado et al., 2002). Research has also shown that African Americans may be more likely to express a willingness to participate if the researcher is of the same race (Armstrong et al., 1999). This finding has underscored the need for the recruitment, training, and inclusion of ethnic minorities at all levels of the research process (Ford et al., 2007) and in the development of a diverse clinical staff, who reflect the ethnic and racial composition of the community.

Minuchin’s work in Structural Family Therapy views “joining” as a key component to the work of psychotherapy. He defines joining as “the therapist’s methods of creating a therapeutic system and positioning himself as its leader” Minuchin (1974, p. 123). Like Boyd-Franklin (2003), Minuchin (1974) believes that this relationship is vital for establishing trust and setting up a strong foundation for the therapeutic work. Diamond et al. (2006) provided research to further explore Boyd-Franklin’s (2003) and Minuchin’s (1974) concept of the importance of “joining” with a client. By creating a trusting relationship for the client, Diamond et al. (2006) found that clients showed a positive outcome and were more successful in their therapy, as rated by decrease drug use.

The work of Mitrani et al. (2003), Perrino, Coatsworth, Brones, Pantin, and Szapocznik (2001), and Prado et al. (2002) with African Americans, Hispanics, HIV+ asymptomatic African-American women, and substance abusing adults considered the complexities of culture and ethnic differences and their role in psychotherapy. They found that initial efforts to engage and build a therapeutic alliance played a considerable role in the retention of these patients and the relief of psychological distress in these families. Also contributing to this work was the understanding of the complexities of culture and ethnic differences and their role in psychotherapy. It is also important for clinicians to recognize that concrete issues, such as poverty, homelessness, fears about safety, and community violence, may need to be addressed first in order to establish credibility and to build trust in the treatment process (Boyd-Franklin, 2003; Boyd-Franklin & Bry, 2000).

In addition, just as flexibility in scheduling research interventions in the evening and on weekends can increase research participation; it can also increase the likelihood of family participation in treatment. Similarly, outreach including home-based family and community interventions can lead to a greater involvement of central family and extended family members (Schwartz et al., 2007) and may have an impact on treatment outcome (Boyd-Franklin & Bry, 2000).

Finally, consideration should be given to how we advance culturally sensitive clinical and research assessment tools. Alderfer et al. (2007) using Chambless and Ollendick’s (2001) three tier hierarchical classification system as a guide, evaluated 29 Family Measures. Criteria separated the measures into three groups, “well established,” “approaching established,” and “promising assessments.” The work of Alderfer et al. (2007) is comprehensive in that many of the measures have been adapted for diverse groups making the results generalizable. A next step in advancing family assessment will be to support the participation of multiple informants that play major roles in family functioning—grandparents, aunts, uncles, close friends, as part of understanding nontraditional family structures.

Summary and Recommended Next Steps in Family Assessment Research

Clinical-research integration and diversity in family assessment research will be enhanced by some overarching recommendations which are informed by the literature. With multiculturalism growing in our society, researchers who conduct large and multi-site studies that include family variables could examine the relationships between race/ethnicity, demographic, and pediatric outcome variables. Given that most studies collect this information, such analyses are possible. In doing so, it is important to remember, that sensitive interpretation is needed when differences are noted.

It is also important to validate measures for pediatric subpopulations. This process was demonstrated in the current issue by Celano and colleagues who examined the validity of the Family Asthma Management Systems Scale.
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